

111TH CONGRESS  
1ST SESSION

# H. R. 653

To amend title IV of the Public Health Service Act to create a National Childhood Brain Tumor Prevention Network to provide grants and coordinate research with respect to the causes of and risk factors associated with childhood brain tumors, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JANUARY 22, 2009

Ms. LEE of California introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To amend title IV of the Public Health Service Act to create a National Childhood Brain Tumor Prevention Network to provide grants and coordinate research with respect to the causes of and risk factors associated with childhood brain tumors, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “National Childhood  
5 Brain Tumor Prevention Network Act of 2009”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

1           (1) Tumors kill more children than any other  
2 disease and brain tumors are the second most com-  
3 mon type of cancer in children.

4           (2) Childhood brain tumors are the leading  
5 cause of death from solid tumors in children.

6           (3) There are newly recognized types of brain  
7 tumors, as defined by the World Health Organiza-  
8 tion, and many of these newly recognized types  
9 occur in children.

10          (4) The causes of the overwhelming majority of  
11 childhood brain tumors are unknown.

12          (5) Brain tumors have substantial costs for af-  
13 fected children, the families of such children, and so-  
14 ciety.

15          (6) Childhood brain tumors cause significant  
16 morbidity and the loss of many years of potential  
17 life.

18          (7) The prognosis for most childhood brain tu-  
19 mors is dismal and survivors face lasting adverse  
20 health effects.

21          (8) Because of the relatively low overall inci-  
22 dence of childhood brain tumors, such tumors fre-  
23 quently do not receive sufficient attention and re-  
24 search funding.

1           (9) No single institution has a sufficient num-  
2 ber of patients to independently conduct research  
3 that will adequately address the causes of childhood  
4 brain tumors.

5           (10) There has been no comprehensive study  
6 analyzing all relevant clinical, biological, and epide-  
7 miological aspects of childhood brain tumors to iden-  
8 tify potential risk factors and determine the cause of  
9 such tumors.

10          (11) Existing national cooperative clinical on-  
11 cology groups primarily investigate treatment op-  
12 tions and prognosis and do not typically examine the  
13 origins of childhood brain tumors or the risk factors  
14 associated with such tumors. A significant majority  
15 of children with brain tumors are first treated by  
16 neurosurgeons and not by oncologists typically in-  
17 volved in such groups.

18 **SEC. 3. SENSE OF CONGRESS.**

19 It is the sense of Congress that—

20          (1) there is a need to establish a multi-center  
21 research effort based on collaboration between re-  
22 gional consortia in order to comprehensively study  
23 the causes of childhood brain tumors and identify  
24 potential risk factors;

1           (2) there is a need to encourage a collaborative  
2 effort among surgical and medical centers with epi-  
3 demiological study groups to gather comprehensive  
4 and detailed information for each child enrolled in  
5 those groups, in order to investigate environmental,  
6 nutritional, genetic, and developmental factors with  
7 respect to, and the pathological and epidemiological  
8 characteristics of, childhood brain tumors; and

9           (3) there is a need to authorize the Director of  
10 the National Institutes of Health to coordinate na-  
11 tional research efforts of governmental and non-  
12 governmental entities with respect to childhood brain  
13 tumors.

14 **SEC. 4. ESTABLISHMENT OF THE NATIONAL CHILDHOOD**  
15 **BRAIN TUMOR PREVENTION NETWORK.**

16       (a) IN GENERAL.—Subpart 1 of part C of title IV  
17 of the Public Health Service Act (42 U.S.C. 285 et seq.)  
18 is amended by adding at the end the following:

19 **“SEC. 417G. NATIONAL CHILDHOOD BRAIN TUMOR PREVEN-**  
20 **TION NETWORK.**

21       “(a) ESTABLISHMENT OF THE NATIONAL CHILD-  
22 HOOD BRAIN TUMOR PREVENTION NETWORK.—

23           “(1) IN GENERAL.—Not later than one year  
24 after the date of the enactment of this section, the  
25 Director of NIH, acting through the Director of the

1 National Cancer Institute, shall establish, admin-  
2 ister, and coordinate a National Childhood Brain  
3 Tumor Prevention Network (hereinafter referred to  
4 in this section as the ‘Network’) for the purposes de-  
5 scribed in paragraph (2).

6 “(2) PURPOSES.—The purposes of the Network  
7 shall be the following:

8 “(A) Providing grants of not fewer than  
9 five years duration to eligible consortia for the  
10 purpose of conducting research with respect to  
11 the causes of and risk factors associated with  
12 childhood brain tumors.

13 “(B) Assembling a panel of experts, in-  
14 cluding members of the Brain Tumor Epidemi-  
15 ology Consortium and survivors of brain tu-  
16 mors, to provide ongoing guidance and rec-  
17 ommendations for, with respect to research  
18 funded by the Network, the development of the  
19 following:

20 “(i) A common study design.

21 “(ii) Standard protocols, methods,  
22 procedures, and assays for collecting from  
23 individuals enrolled as study participants,  
24 and the parents of such individuals, a min-  
25 imum data set that includes the following:

1                   “(I) Environmental exposure  
2 data.

3                   “(II) Nutritional data.

4                   “(III) Biospecimens, including  
5 genomic data.

6                   “(IV) Histopathological and mo-  
7 lecular pathological data and speci-  
8 mens.

9                   “(V) Clinical and radiological  
10 data.

11                   “(iii) Specific analytical methods for  
12 examining data.

13                   “(iv) Provisions for consensus review  
14 of enrolled cases.

15                   “(v) An integrated data collection net-  
16 work.

17                   “(C) Designating a central laboratory to  
18 collect, analyze, and aggregate data with re-  
19 spect to research funded by the Network and to  
20 make such data and analysis available to re-  
21 searchers.

22                   “(3) ELIGIBLE CONSORTIA.—To be eligible for  
23 a grant under this section, a consortium shall dem-  
24 onstrate the following:

1           “(A) The capability to annually enroll as  
2           research participants a minimum of 100 indi-  
3           viduals with a newly diagnosed childhood brain  
4           tumor from the designated catchment area of  
5           such consortium.

6           “(B) The capability to form a control  
7           group by enrolling as research participants, for  
8           each enrolled individual with a childhood brain  
9           tumor, at least two individuals without a child-  
10          hood brain tumor, who are matched demo-  
11          graphically to such enrolled individual with a  
12          childhood brain tumor.

13          “(C) That the designated catchment area  
14          of such consortium does not overlap with the  
15          designated catchment area of a consortium al-  
16          ready receiving a grant under this section.

17          “(4) REPORT.—Not later than one year after  
18          the date of the enactment of this section and annu-  
19          ally thereafter, the Director of NIH shall submit to  
20          Congress a report with respect to the Network, to be  
21          made publicly available, including a summary of re-  
22          search funded by the Network and a list of consortia  
23          receiving grants under the Network. At the discre-  
24          tion of the Director of NIH, such report may be  
25          combined with other similar or existing reports.

1           “(5) AUTHORIZATION OF APPROPRIATIONS.—

2                   “(A) IN GENERAL.—There is authorized to  
3           be appropriated \$25,000,000 for each of fiscal  
4           years 2010 through 2014, to remain available  
5           until expended, to carry out this section.

6                   “(B) SENSE OF CONGRESS.—It is the  
7           sense of Congress that funds appropriated to  
8           carry out this section should be in addition to  
9           the funds already appropriated to carry out the  
10          functions of the National Institutes of Health.

11          “(b) DEFINITIONS.—For purposes of this section, the  
12         following definitions apply:

13                   “(1) BRAIN TUMOR EPIDEMIOLOGY CONSOR-  
14           TIUM.—The term ‘Brain Tumor Epidemiology Con-  
15           sortium’ means the organization with such name  
16           formed in 2003 after an initial meeting sponsored by  
17           the National Cancer Institute’s Division of Cancer  
18           Epidemiology and Genetics.

19                   “(2) CATCHMENT AREA.—The term ‘catchment  
20           area’ means a defined area for which population  
21           data are available.

22                   “(3) CHILDHOOD BRAIN TUMOR.—The term  
23           ‘childhood brain tumor’ means an intracranial or  
24           spinal cord tumor occurring in an individual under  
25           20 years of age.



1           “(4) CONSORTIUM.—The term ‘consortium’  
2 means a partnership of two or more universities,  
3 health care organizations, or government agencies,  
4 or any combination of such entities, serving a des-  
5 ignated catchment area.”.

6           (b) TECHNICAL CORRECTION.—

7           (1) IN GENERAL.—Section 3 of the  
8 Hematological Cancer Research Investment and  
9 Education Act of 2002 (Public Law 107–172; 116  
10 Stat. 541) is amended by striking “419C” and in-  
11 sserting “417C”.

12           (2) EFFECTIVE DATE.—The amendment made  
13 by paragraph (1) shall take effect as if included in  
14 the enactment of the Act referred to in such para-  
15 graph.

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